

# Approach to hoarding in family medicine

## *Beyond reality television*

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### Abstract

**Objective** To review the presentation of hoarding and provide basic management approaches and resources for family physicians.

**Sources of information** PubMed was searched from 2001 to May 2011. The MeSH term *hoarding* was used to identify research and review articles related to the neuropsychological aspects of hoarding and its diagnosis and treatment.

**Main message** Hoarding is often a hidden issue in family medicine. Patients with hoarding problems often present with a sentinel event such as a fall or residential fire. Although hoarding is traditionally associated with obsessive-compulsive disorder, patients more commonly have secondary organic disease associated with hoarding behaviour or have hoarding in absence of substantial compulsive traits. Hoarding disorder is expected to be included in the *Diagnostic and Statistical Manual of Mental Disorders*, 5th edition. Management is best provided by a multidisciplinary approach when possible, and an increasing number of centres provide programs to improve symptoms or to reduce harm. Pharmacologic management has been shown to be of some help for treating secondary causes. In the elderly, conditions such as dementia, depression, and substance abuse are commonly associated with hoarding behaviour. Attempts should be made to keep patients in their homes whenever possible, but an assessment of capacity should guide the approach taken.

**Conclusion** Hoarding is more common than family physicians realize. If hoarding is identified, local resources should be sought to assist in management. Assessment and treatment of underlying causes should be initiated when secondary causes are found. It is expected that primary hoarding will be a new diagnosis in the *Diagnostic and Statistical Manual of Mental Disorders*, 5th edition.

Although hoarding has received a great degree of attention in the media, it remains a hidden problem in family medicine. Patients with pathologic hoarding behaviour, particularly elderly patients, are often identified by a sentinel event such as a fall or residential fire when their home situation becomes a crisis. Treatment of hoarding is notoriously challenging and raises many ethical and legal issues related to safety and capacity.

This paper will review the presentation of hoarding and basic management approaches and resources for family physicians.

### Case

Ms L., an 86-year-old woman, was admitted to hospital after her friend found her lying on the living room floor. The friend drove Ms L. to the grocery store each week, but she had not been in the home before, as Ms L. had always met her at the end of the driveway. Ms L. was brought by emergency medical services staff to the emergency department, where she was admitted with a urinary tract infection and renal failure due to rhabdomyolysis. Her medical condition stabilized quickly, and she was referred for geriatric rehabilitation to help her return home. The hospital chart documented that the

**KEY POINTS** Hoarding behaviour is more common than reported, and family physicians should be alert to its presence, particularly in older patients. Hoarding might arise from a primary mental health disorder or be the result of secondary causes such as dementia, stroke, or brain injury. Treatment should be multidisciplinary, with the goal of reducing harm and allowing patients to remain at home except in circumstances of severe risk or decisional incapacity. Pharmacologic treatment of secondary causes can be helpful.

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ambulance staff reported that the house was in “poor shape,” but not until the friend contacted a social worker with photos of the inside of Ms L.’s house was the extent of the problem clear.

Ms L. did very well during her rehabilitation stay and might have been physically able to return home, save for the deplorable conditions inside of her house that raised questions about her capacity. The Public Guardian and Trustee became involved after a subsequent finding of financial incapacity; the patient’s home was padlocked after a building inspector refused to enter the premises owing to safety concerns.

## Sources of information

PubMed was searched from 2001 to May 2011. The MeSH term *hoarding* was used to identify research and review articles related to the neuropsychological aspects of hoarding and its diagnosis and treatment. Most research was limited by small samples and by mixed populations of patients with hoarding and obsessive-compulsive disorder (OCD).

## Main messages

**Epidemiology.** Hoarding behaviour is found in at least 2% to 5% of the population<sup>1</sup> and it can have substantial individual and societal costs. The city of San Francisco, Calif, estimated the annual cost of dealing with hoarding to be \$6.5 million, excluding the cost of health care workers involved in care.<sup>2</sup> Fire officials in Melbourne, Australia, found that hoarding was a factor in 25% of fires deemed to be preventable.

Although the prevalence of hoarding is higher among older patients, most people with hoarding behaviour not due to identifiable organic causes (ie, primary hoarding or hoarding disorder) start to show signs in adolescence or young adulthood.<sup>3</sup> Falls are the most common event unmasking borderline living situations.

**Terminology and definitions.** Hoarding is a complex set of behaviour that exists on a continuum—from being a messy and very disorganized collector at one end to living in abject filth and squalor at the other. The latter situation occurs as affected individuals’ usually worthless material possessions invade their homes and essentially take over their lives, negatively affecting their quality of life.<sup>4</sup>

The conceptualization and nomenclature of hoarding are currently undergoing revision. The *Diagnostic and Statistical Manual of Mental Disorders* (DSM), 4th edition, includes hoarding behaviour as 1 of 8 criteria for OCD, and the traditional view has been of hoarding as a subtype of OCD. There are DSM-V criteria for a newly proposed *hoarding disorder* in development,<sup>5</sup> but in practical terms, *hoarding* can be defined as a behavioural disorder characterized by the following:

- the excessive accumulation of material possessions of dubious value and quality;
- the character and quantity of such possessions substantially interferes with an individual’s normal social, functional, and vocational roles;
- the individual cannot or will not willingly part with these possessions; and finally
- the individual often lacks insight into the safety risk their possessions can cause. Note that the safety risks can be direct (eg, spoiled food that is not discarded, fire hazard from the accumulation of combustibles, piles toppling onto persons or pathways through home) or indirect (eg, possessions becoming home to pests and vermin, possessions interfering with the ability to prepare and eat meals, important items such as outstanding bills and medications lost in the clutter).

Some authors suggest viewing hoarding as either being due to organic illness or as a primary condition, sometimes termed *hoarding disorder*. *Compulsive hoarding* should be used only for describing the problem when it occurs in conjunction with OCD. Hoarding disorder is more likely to be seen in younger patients.<sup>1</sup>

Organic hoarding due to secondary conditions is more common in older patients, owing to a higher likelihood of concurrent conditions. These include dementia, particularly frontotemporal lobar degeneration (FTLD), stroke, alcoholism, and severe depression. Brain injury patients might display hoarding behaviour, and they provide a model for the biologic and anatomic basis of organic hoarding. Schizophrenia can present late in life and might also cause hoarding behaviour. A prospective study of referrals to geriatric psychiatry in Sydney, Australia, found that the causes of moderate to severe squalor were dementia (35%), substance abuse (24%), schizophrenia (15%), and personality disorder (7%), with the remainder owing to physical illness, depression, or no definite diagnosis.<sup>6</sup> **Box 1** describes features suggestive of the presence of organic causes.<sup>7,8</sup>

There is a strong association between hoarding and other mental health conditions. Although OCD was thought to be the main connection, hoarding is more strongly associated with anxiety disorders such as social phobias and generalized anxiety disorder. Substance abuse is commonly related to hoarding behaviour. Specific personality disorders have also been related to increased risk, most notably dependent, avoidant, schizotypal, and obsessive-compulsive personality disorders. The role these personality traits play is unclear, but they might predispose patients to respond to triggering events such as bereavement or illness.<sup>1,8-12</sup>

One of the terms used to categorize extreme hoarding behaviour with severe squalor is *Diogenes syndrome*, named after the Greek philosopher who chose to live in poverty (most famously in a barrel) and who eschewed societal norms. This term arose from a 1975

### Box 1. Clues hoarding might be secondary to an underlying medical condition

The following are clues that hoarding might be secondary to an underlying medical condition:

- Onset later in life
- Passive rather than active accumulation of items (eg, failure to take out the garbage or recycling, stacking old newspapers)
- Objective cognitive impairments (eg, short-term memory loss, long-term memory loss on testing)
- Subjective memory loss (eg, medication nonadherence; neglecting medical, dental, and other important appointments)
- New overvalued ideas, delusional thinking, and hallucinations (including visual and auditory)
- New decrements in IADLs or BADLs (eg, no longer driving, no longer bathing or changing clothes)
- Ongoing alcohol, medication, or other substance misuse
- New or progressive sensory impairments (eg, vision and smell)
- New or progressive CNS disease (eg, stroke, Parkinson disease)

BADL—basic activities of daily living, CNS—central nervous system, IADL—instrumental activities of daily living.

Data from Gregory et al<sup>7</sup> and Mataix-Cols et al.<sup>8</sup>

case series in the *Lancet*<sup>13</sup> but has come under criticism as a misnomer. Patients with Diogenes syndrome display hoarding along with poor hygiene, social isolation, and indifference to their living situation, and usually have untreated medical conditions and sequelae of neglect (eg, insect bites, infections related to personal and food hygiene). Regardless of the historical accuracy of the term, it should be used only to describe a specific subset of patients with hoarding behaviour and should not be used interchangeably with *hoarding disorder*.

**Biologic basis.** Animal models using creatures that hoard as part of their survival strategy (eg, magpies, pack rats) and human acquired brain injury models have provided some insight into the biologic basis of hoarding behaviour. Functional imaging suggests that the medial prefrontal area of the brain plays an important role. Symptom provocation studies also link hoarding to the anterior cingulate cortex, along with other limbic structures. Dopamine is thought to play a role based on animal models; dopamine-deficient animals have been shown to resume hoarding behaviour when given levodopa.<sup>8</sup>

It is much harder to determine the biologic basis of nonorganic hoarding, in which there is no identifiable neurologic cause or injury. Similar areas of the brain have been shown to be affected, but the studies are limited by small sample sizes and mixed populations of subjects with hoarding disorder and OCD. It does appear that OCD patients without hoarding behaviour show activity in different areas of the brain than compulsive (OCD) hoarders.<sup>9,11</sup>

Usually, FTLT presents in patients younger than 70 years of age; 10% of cases present in those older than age 70, reflecting differences in underlying pathology.<sup>14</sup> Clinically, patients with FTLT and hoarding behaviour might not show deficits on common tests of frontal lobe function, such as the Frontal Assessment Battery, but they might have abnormal findings on testing of more medial function. The Iowa Gambling Task, which assesses medial-frontal function, has been shown to have positive findings in patients with frontal dementia and concurrent hoarding behaviour. This is not a test commonly done by family physicians, but it does highlight that more common frontal lobe testing might have limitations.<sup>8</sup>

**Management and ethical issues.** Health care professionals, families, and landlords find management of hoarding behaviour very challenging. A common feature of organic hoarding is a lack of interest in changing and diminished concern about societal norms. Conversely, patients with nonorganic hoarding might feel considerable distress about the possessions and junk overwhelming them but have great difficulty tolerating the distress caused by losing those possessions, and they are often resistant to interventions. This resistance is less common in patients with dementia and hoarding, but their cognitive issues raise other management and safety issues.

Like many complex health problems, the principle of management is providing an interdisciplinary approach. Guidelines from Australia provide a possible approach to hoarding.<sup>15</sup> In most areas a coordinated approach is limited or has only become recently available, and physicians in smaller communities and larger towns or small cities might have limited access to specific programs or services. Municipalities, recognizing the social and economic cost of hoarding, are developing guidelines and “extreme cleaning” teams. The family physician’s initial role is in recognition and evaluation of medical and psychiatric comorbidities causing or contributing to the disorder. Treatment of health problems arising directly from the condition, such as edema, cellulitis, and malnutrition, will commonly fall to the family physician.

The goal of treatment is usually to try to improve the situation without removing the patient from the home,<sup>16</sup> except in situations of extreme risk or incapacity. Institutionalization of elderly patients with hoarding disorder or Diogenes syndrome might result in increased mortality. Likewise, aggressive removal of items and “extreme cleaning” might lead to considerable distress without decreasing the risk of the patient returning to the behaviour in the same location or wherever the person moves (or is moved to). Most agencies involved in hoarding management will use a stepwise approach to cleanup and decluttering when the patient is engaged

in the process and does not have substantial dementia or comorbid psychiatric conditions. Harm reduction, a strategy used in treating substance abuse, has been shown to have benefit for hoarding patients and their families.<sup>17</sup> The process of treatment can take months to years.

Pharmacologic and nonpharmacologic treatments have been studied for patients with OCD symptoms associated with hoarding or for hoarding that is thought to be due to OCD. Cognitive behavioural therapy is the most commonly cited approach and has been shown to be effective in up to 50% of people.<sup>18,19</sup>

Pharmacologically, there is little high-quality evidence for benefit of medications.<sup>20,21</sup> Saxena recently published an open-label study showing positive effects using serotonin reuptake inhibitors (both selective serotonin reuptake inhibitors and serotonin norepinephrine reuptake inhibitors) in OCD and non-OCD hoarding using paroxetine and venlafaxine, with the latter agent being particularly effective.<sup>21</sup> Treatment of dementia with cholinesterase inhibitors or memantine (for moderate to severe Alzheimer disease) can be considered, but patient safety and adherence are obvious concerns. In patients with behaviour variant frontotemporal dementia, selective serotonin reuptake inhibitors and atypical neuroleptics are sometimes used to treat disinhibition, agitation, and aggressive behaviour; there are no published studies to show whether these medications improve hoarding. Despite a lack of randomized controlled trials, memantine is sometimes used by frontotemporal dementia experts, but there is no evidence of benefit for hoarding behaviour. The use of antipsychotics in OCD-related hoarding is not recommended unless psychosis is present. Treatment of psychiatric diseases contributing to hoarding behaviour, such as severe depression and schizophrenia or psychosis, might decrease hoarding symptoms, especially if apathy is a factor in clutter or squalor. An antipsychotic medication might be indicated if a thought disorder is driving the behaviour (eg, a patient with schizophrenia collecting rubbish because the voices in his head are telling him to do so, or a patient with dementia saving used coffee cups because of a delusion they are valuable), assuming the benefits outweigh the recognized risks.

Given the increased awareness of the problem of hoarding, multidisciplinary models of care and Web listings of resources are becoming more common.<sup>22-24</sup> An example is the Gatekeepers Program in Hamilton, Ont, which identifies potential clients by training non-health care staff such as bank tellers and postal workers (and even the beer delivery man) to recognize signs of hoarding and refer individuals of concern to a central intake office. The Gatekeeper approach provides multidisciplinary support and advocacy for the vulnerable elderly hoarder through case management. Decreasing social isolation, reducing safety risks (eg, by helping to

reduced excess clutter and unsanitary living conditions), and connecting such hoarders to community support programs is thought to improve quality of life and reduce the need for unplanned hospitalization.<sup>25</sup> Long-term monitoring also takes place for those enrolled in the program. Similar programs exist in Vancouver, BC, and Calgary, Alta, and in Toronto, Ottawa, and Kingston in Ontario, but we did not find a central listing of coalitions and treatment programs when we did a Web search.

When involved with hoarding situations, it is hard to not feel the sentiments described by an American task force:

Everyone working in Adult Protective Services and Elder Abuse and Neglect Offices knows that referrals of people who hoard will be simultaneously amazing and confounding. Can a person possibly be both legally competent and living on top of three feet of a mix of garbage and newly purchased gifts, trinkets, and food? Or living in an apartment or home in which all but one small corner of one room is totally filled? Or living amid a few dozen pets and their waste?<sup>26</sup>

One of the biggest management dilemmas is clarifying patient capacity to decide to remain in a potentially hazardous environment. The ability to make personal care and financial capacity decisions might be affected, depending on the cause of the hoarding. Patients with dementia or other mental health diagnoses might lack the ability to understand and appreciate the nature of their situation and the risks. People with nonorganic hoarding commonly lack insight into how far from societal norms their behaviour has strayed, but they often are able to identify the risks and justify their choices. Removal of the patient from their home without considering capacity is not only unethical but, as noted earlier, might not always be in the patient's best interest.

## Case resolution

Ms L. was found to be incapable of making financial decisions based on her use of limited resources to buy unnecessary items and the fact that she donated substantial sums to a number of charities despite the need for home repairs and necessities of life (she donated to animal welfare funds but had the carcasses of several dogs in garbage bags on her porch). She was found to be incapable of deciding on long-term care placement owing to her insistence on returning home despite full knowledge that her house was condemned. The provincial Public Guardian and Trustee upheld both decisions.

She received a full psychometric evaluation that included frontal lobe testing but that did not emphasize medial frontal lobe tasks. There was no evidence of depression or dementia (including FTLD). No other



psychiatric comorbidities were identified, and she was not treated pharmacologically. She participated in therapy, did not reaccumulate possessions within her room, and was accepting of personal care and assistance with hygiene. She did complain bitterly throughout about the discharge plan and the loss of her house. She remained skeptical about her access to her finances, feeling that the "government" had "stolen" her money.

She was discharged to a nursing home but continually expressed her eventual goal of returning home. The Public Guardian and Trustee remained her substitute decision maker for placement and living situation. The consulting psychiatry service did not provide a diagnostic label but believed Ms L. would meet the proposed criteria in DSM-V for hoarding disorder.

## Conclusion

Hoarding behaviour is more common than reported, and family physicians should be alert to its presence, particularly in older patients. Hoarding might arise from a primary mental health disorder or be the result of secondary causes such as dementia, stroke, or brain injury. Treatment should be multidisciplinary, with the goal of reducing harm and allowing patients to remain at home except in circumstances of severe risk or decisional incapacity. Pharmacologic treatment of secondary causes can be helpful.

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Both authors contributed to the literature review and preparing the manuscript for publication.

### Competing interests

None declared

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